

Challenges of Persons with Disabilities in the “Calabar” Community of Salvador da Bahia

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Abstract

This project is written by Marilena Juettemeier as for fulfilment of the Master of Special Needs Education at the University of Oslo. The master thesis consists of the extended summary and the manuscript "Challenges of persons with disabilities in the "Calabar" community of Salvador da Bahia" aimed for publication in the Journal of International Special Needs Education. The extended summary aims to clarify the theory and context of ecological theory and Brazil, outlining the rationale behind implemented methodological choices. The article manuscript investigates the impact of different systems on the daily lives of persons with disabilities in the Calabar community, as understood through ecological analysis. Face-to-face interviews were conducted with eight participants consisting of three persons with disabilities, two caregivers, and three community leaders from the Calabar community, augmented by naturalistic observations. Results are shortly reported then discussed in light of the four major emerged themes. Findings outline several challenges across differing systems, with physical accessibility being the most commonly reoccurring challenge mentioned. Challenges found highlight the need for the current investigation. Future research recommendations for improvements of challenges are outlined.

Preface

I would like to thank my friends and family for their unparalleled support during the last two years of a master's degree abroad. My supervisor Dr Luca Tateo, has provided invaluable guidance, and the opportunity to take part in a research-tandem project in Brazil, for which I am grateful. It has resulted in me meeting my tandem-partner, who assisted the entirety of the project through her valuable cultural insights and translations. I would also like to thank Professor Maria Virginia Dazzani and her research group for the vital support during our research-exchange in Brazil. All of the aforementioned opportunities I can only describe as life-changing, acquiring vital experience within another local setting and making lifelong friends and research partners throughout the process.

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1 Introduction

1.1 The two Thesis Parts and their Connection

The extended summary provides the reader with a comprehensive understanding of the chosen Brazilian context, Calabar da Bahia specifically. Specific intersectional factors affecting individuals with disabilities in the context will further be explained. It is followed by the theoretical background of ecological theory and the rationale of using this approach. Rationale for methodological choices will be outlined, due to space limitations in the article manuscript. Undertaken analysis is explained and emerged themes are summarized shortly. The discussion recaps the major themes, strengths and weaknesses, and associated impacts for future research and implications.

The manuscript aims to answer the research question raised, using the data collected from the face-to-face semi-structured interviews with persons with disabilities, caregivers, and community leaders in the Calabar community. The authors name is not mentioned on the title page of the manuscript to abide by blind submission guidelines, and appropriate formatting adjustments including running head, page numbers, and line spacing made to the manuscript, fulfilling requirements of the Journal of International Special Needs Education (Appendix A).

1.1.1 Research-tandem Explanation

The current thesis project is part of a research-tandem exchange between the Department of Special Needs Education at the University of Oslo, Norway, and the Postgraduate Program in Psychology at the Federal University of Bahia, Salvador da Bahia, Brazil. The author of the thesis was paired with a local research-tandem student in Bahia and collected all data in Brazil during the 3-month exchange period from January to March 2023. The project is designed to increase the mutual learning about cultures and decrease the borders among scholars (University of Oslo, 2023).

1.1.2 Rationale for the Intended Journal

The master student selected the Journal of International Special Needs Education as the intended journal in collaboration with the thesis supervisor. The research-tandem project provided the student with the opportunity of a cultural exchange and data collection in Brazil. It fits within the scope of the chosen journal due to its disability focus in a range of ethnic, cultural, geographic, and language backgrounds (Journal of International Special Needs Education, 2023). The project includes ecological theory as it affects persons with disabilities in daily living within the Calabar community. Although the project focuses in a specific

Brazilian context, the implications are essential to consider for Western and global contexts. Therefore, the scope is aligned with the intended diverse audience of the chosen journal.

1.2 The Research Problem

Persons with disabilities are exposed to unique challenges daily, including accessing healthcare, transportation, education, and participation in social surroundings or the workforce (Castellani et al., 2022). These challenges are exacerbated especially in developing countries via a lack of appropriate support systems and resources in local communities (Ae-Ngibise et al., 2015). Within Brazil, one of the largest non-WEIRD (Western, educated, industrialized, rich, democratic) countries globally, disability research is scarce, particularly in low-resource communities like Calabar da Bahia, where limited resources and infrastructure, and social disparities may exacerbate barriers for individuals with disabilities (Oxfam, 2022). The neighbourhood also demonstrates intersections with disability and ethnicity and poverty, with majority Afro descendants and low socio-economic standing (Treuke 2019a). Focusing on intersections of factors is essential to determine different needs across countries, regions, or specific population groups, with a current lack of intersection focus world-wide even in highly developed nations such as Norway, despite research supporting factors like ethnicity exaggerating barriers for individuals with disabilities (Gjertsen, 2019).

In this setting, understanding the impact of different ecological systems on individuals with disabilities and differing disadvantaging factors is vital, to provide insights that can aid the development of interventions and policies to improve quality of life (Olivier-Pijpers et al., 2020b). Thus, the current study investigated the ecological factors that influence the experiences of persons with disabilities in Calabar. Through comprehension of the complex web of cultural, social, and economic aspects that affect individuals with disabilities in their daily lives, the study provides a comprehensive understanding of factors that facilitate and hinder quality of life of individuals with disabilities in the given context (Haythorne et al., 2022). To investigate research problems, the following question was formulated:

- What is the impact of different ecological systems on persons with disabilities in the Calabar community in daily life?

2 Brazil and Calabar as a Chosen Context

Brazil was strategically chosen as a location to bridge knowledge gaps about non-WEIRD countries, going beyond the WEIRD country and especially US based dominance of research (Chang et al., 2022). This research bias creates false depictions of human behaviour, assuming that findings from developed nations are generalizable on a global basis (Jones, 2010). Despite touting one of the largest economies worldwide, approximately 28 million people of a total of 212 million people live in poverty within Brazil (Oxfam, 2022). Prior research outlines the economic and social inequalities across the fifth biggest country of the world, but there is a lack of research within the field of disability (Oliveira et al., 2023). This is particularly problematic as Brazil is one of the heaviest populated countries, with approximately 16 million people with disabilities (Oxfam, 2022).

When considering developing nations, there are vast differences between disability support across ethnicities and socio-economic standings, despite Brazilian law stating that all individuals possess the same rights and resources (De Sales Lima et al., 2021). Evidence suggests an important intersection between disability and ethnicity, specifically African heritage, in the given context further exaggerating barriers individuals with disabilities face (Bagni, 2023). Additionally, social inequities, especially based on socio-economic standing, displayed differences in access to rehabilitation services for individuals with disabilities across Brazil, outlining a necessity to formulate and ensure implementation of policies that ensure the rights of persons with disabilities (Medeiros et al., 2021). A study with data from the National Health Survey revealed that self-reported prevalence of disability varied by sex, age, ethnicity, and place of residence, with people above 60 and from the Northeast of Brazil showing higher prevalence of disability (Malta et al., 2016). These findings not only further support the need for strengthened public policies for individuals with disabilities, expanded health promotion and target it to different groups, but also the need to investigate regions that are prone to have higher prevalence of disability.

Focusing the disability research to Salvador da Bahia allows for numerous intersections to be explored, with the Northeast of Brazil being historically on a lower socio-economically level, and Salvador being the city with the highest population of people with African descent outside of Africa (Treuke, 2019a). Several prior studies focused on individuals with disability as a homogenous minority group, often disregarding the impact of belonging to several minority groups through different intersections (Warner & Brown, 2011).

2.1 Salvador da Bahia and Calabar Historic Roots

Salvador da Bahia and the suburb of Calabar was chosen as a location for its intersectionality of varying influential factors such as socio-economic status and ethnicity, especially important for providing a comprehensive representation of the challenges of persons with disabilities (Treuke, 2019a). The city was the first colonial capital of Brazil and remained so for nearly 200 years, being the city with the first market of enslaved people (UNESCO, 2023). Growth immediately ensued due to the seaport, sugar trade, and trade of enslaved people. Considering this history, Salvador da Bahia's record setting African population is expected (Treuke, 2019a). This heritage is essential to comprehend in the selection of the Calabar community as the strategically chosen research area.

The Calabar neighbourhood has historically been shaped by the resistance of individuals with African heritage to remain in a prime location of the city centre, a low-socio economic income neighbourhood surrounded by multiple high-income neighbourhoods (Treuke, 2019b). Historian Cid Teixeira states that the name of Calabar originates from the enslaved people that took refuge in the area, this population deriving from an African region called Kalabari, known as Nigeria today (Salvador Cultura Todo Dia, 2006). From the late 1960s onward, exponential growth occurred due to immigration from countryside inhabitants and individuals that were expelled from other parts of the city, with various neighbourhood groups being formed in Calabar to protect the communities basic rights, such as education and health, with the primary group being *Jovens Unidos do Calabar* (Young United Calabar).

Until modern day, the community had different initiatives to not only improve the economic, social, and cultural situation of the community, but also to portray to the government and surrounding neighbourhoods that the community is not solely consisting of drug trafficking and violence and that the community is striving (Freitas et al., 2015). One of the main community initiatives is the local community library, assisting in educational purposes and cultural leisure activities, effectively aiding social transformation and maintenance of local culture through accessible information and inclusive workshops and trainings. Additionally, the community base run by the military police provides work opportunities for women who suffered from domestic violence in form of movable stands to sell sausages and sweets to generate their own income and sport activities for children from disadvantaged families. Nevertheless, despite these community initiatives, it is essential to consider the potential challenges persons with disabilities face every day, particularly in Calabar.

3 The Challenges of Persons with Disabilities

3.1 Access

3.1.1 Physical, Transportation, and Healthcare

Previous evidence suggests individuals with disabilities have challenges regarding access including but not limited to, aspects such as infrastructure (Bonnell et al., 2021). Particularly, physical access to transportation was difficult for individuals with motor disabilities, and wheelchair users in particular, for example ramp slopes in buses being too steep (Bertocci et al., 2019).

Within Brazil, the National Health Policy for People with Disability implemented in 2002 by the Brazilian government addresses different inequalities, the main focus being on six different areas including impairment prevention, organization and functioning of health services, training of human resources, quality of life, comprehensive health care, and quality of life (Da Cunha et al, 2022). Thus, within the Unified Health Care system for all citizens, these issues should be accounted for, despite evidence suggesting that the gradients of health status and the access to services is still majorly dependent on factors such as racial and educational background, and socio-economic standing (Younger, 2016).

Considering healthcare accessibility, evidence from a Sao Paulo study highlighted individuals with multiple or mobility disabilities had more issues accessing healthcare services, particularly if they needed assistance to get to the service, showcasing physical accessibility prevalence to transport (Castro, Cieza et al., 2011). In relation, individuals with motor disabilities had unique struggles related to access even prior to reaching healthcare facilities, including appropriate parking, lack of ramps, elevators, or availability of adapted toilets (Castro, Lefevre et al., 2011). Accessibility issues however were not limited to external spaces, but also internal spaces, and different problematic accessibility features for individuals with hearing or visual impairments (Pinto et al., 2021). Insufficient accessibility to healthcare services for individuals with disabilities is essential to consider as it is a violation of international and Brazilian laws (Da Cunha et al, 2022).

3.1.2 Financial

Financial accessibility is often linked to individuals with disabilities, as many individuals with impairments face various physical and attitudinal barriers in the formal and informal job market (Coelho et al., 2013). Findings support the prevalence of those barriers revealing that employment officers show unconscious stereotypical expectations towards disability, alongside gender and ethnicity, limiting employment opportunities (Dag & Kullberg, 2016). Lower employment rates for individuals with disabilities were outlined

compared to the general Brazilian population, attributed to different factors including prejudice about absenteeism of workers with disabilities and their labour production (Guimaraes et al., 2018). Another associated economic factor in Brazil was the cost-benefit aspects for companies to adequately adapt work environments to the needs of different disabilities (De Guimaraes et al., 2015).

To account for these financial limitations, the Continuous Cash Benefit Program was implemented to support people with disabilities in Brazil, and set an example about how to incorporate the International Classification of Functioning, Disability and Health (ICF) in public policies (Medeiros et al., 2015; Sabariego, 2017). In line with the United Nations Convention on the Rights of Persons with Disabilities, the program uses the eligibility criteria of the ICF of the World Health Organisation to determine benefits for poor elderly and persons with disabilities, aiming to improve social security and access to income by guaranteeing the minimum wage (Bagni et al., 2023; Rabelais Duarte et al., 2017). Despite the program assisting in reducing social inequalities, there are on-going access barriers to receive benefits and intersectoral gaps, with a study including 16% of medical examiners working within the Continuous Cash Benefit Program showing a discrepancy between the actual practice and formal program criteria of medical examiners (Diniz et al., 2007; Sabariego, 2017). Findings suggest that the concept of disability should be expanded to include various forms of disease. However, beyond the various access aspects that influence the daily living of individuals with disabilities, one must consider the different intersections with disability that can further increase barriers.

3.2 Intersectionality and Disability

3.2.1 Poverty

Approximately 25% of the Brazilian population face food insecurity, particularly higher within the Northern regions, for females, and for individuals from African descent (Bagni et al., 2023). Especially for individuals with disabilities, the intersectionality with poverty is important to consider as evidence across Brazil, Chile, Colombia, Costa Rica, and Mexico suggests that families with members with disabilities have higher likelihoods of living in multidimensional poverty (Pinilla-Roncancio, 2018). Evidence from 150 studies, including 70 studies from Brazil demonstrated that there is a strong link between disability and poverty for low and middle income families, outlining a need to adjust and put into place actionable international and national policies to counteract a self-re-enforcing cycle (Banks, 2017). Thus, for many individuals with disabilities the Cash Benefit Program is the main social assistance in Brazil they receive, as it is a social benefit guaranteed by the law. Brazil has different

support benefits guaranteed by law, while however the Cash Benefit Program is the only benefit targeted for individuals with disabilities living in great poverty (Bagni et al., 2023). If individuals are able to prove that they lack the means to support oneself, they theoretically are guaranteed a monthly income to ensure livelihood and quality of life (Stopa, 2019).

3.2.2 Discrimination and Racism

Within Brazil many individuals with disabilities face discrimination and racism on a daily basis, with some individuals being discriminated against simply due to their disabilities, while others are discriminated due to additional factors such as ethnicity (Serrano & Martin, 2021). As a response to the continuing local structural racism within Salvador da Bahia one can find symbols that demonstrate the culture of struggle, symbolised by the Movimento de Negro (Movement of Black), celebrating the heritage and representation of Afro-descent across the entire city (Rizzo, 2022). Evidence found a lack of specific practices that counter institutional racism in Salvador da Bahia, as there are official programs by the Brazilian national health system, to counteract the issues, yet there is an ongoing lack of visibility within aspects such as psychological training and practice (Jesus et al., 2020). In relation to health matters institutional racism amplifies inequalities between Black and Caucasians in Salvador with inter-institutional policies needed with the objective to counteract discriminatory practices of exposure (Oliveira Santana et al., 2020). Especially Black women within Salvador da Bahia face a double discrimination due to the intersectionality of gender and racism, and evidence outlines the need for affirmative action and the need of a political presence to ensure equity to all groups of society (McCallum, 2007). Poverty and discrimination are therefore essential intersections to consider, especially when taking into account the different ecological systems influencing individuals with disabilities in everyday life.

4 Choice of Theory

Several theories have been used across disability research to analyse the differing challenges of persons with disabilities in everyday life such as social identity theory or the integrative bio-psycho-social model of functioning, disability, and health (Lundquist Wanneberg, 2014; World Health Organization, 2001). Despite both of these theories being useful to evaluate the immediate systems of individuals with disabilities and associate challenges, they do not specifically focus on the broader interplay of the different systems ecological theory takes into consideration when analysing the impacts on the individual. Thus, ecological theory was chosen as it considers the social, environmental, and personal factors that impact the everyday life of individuals with disabilities (Kaderavek, 2011). Ecological theory can be used to take a more holistic approach to comprehending disability and the varying impacts of different system, as it considers that disability is not only individual focused, but rather dependent on dynamic and complex interactions of individuals with their environments (Panopoulos & Drossinou-Korea, 2020). This theory accounts for that support and resources of society or support systems can profoundly impact individuals life, and assist in understanding how through different systems individuals with disabilities can be supported in an empowering and effective way, or how the environment might create additional hindrances (Olivier-Pijpers et al., 2020a). Based on the choice of theory, the theory itself and the influences of the different systems will be outlined in the following section.

4.1 Ecological Theory

The ecological theory developed by Urin Bronfenbrenner connects various interrelated system with the individual attributes of each individual such as age (Kaderavek, 2011). There are five systems including the microsystem, such as family, the mesosystem, which demonstrated the interactions between the micro and exosystems, the exosystem such as mass media, the macrosystem such as ideologies of a culture, and the chronosystem, which places all systems in the sociohistorical conditions, with all systems constantly influencing each individual during the course of their lives. All the systems play an essential role in understanding the challenges persons with disabilities face in Calabar.

4.1.1 Individual Attributes

Individuals interact with various systems essential to comprehend to understand the various challenges of individuals, while however being vary of the differences in personal factors that influence interactions (Kaderavek, 2011). Individuals with disabilities are influenced by aspects such as their mood, outgoingness, communicability, up-bringing, self-esteem, age, gender, or how disabilities were acquired (Coelho et al., 2013). The most

commonly focused personal factors within disability research however are age, gender and ethnicity. Considering age and disability in combination is essential, as previous evidence suggests that based on age-related prejudice individuals tend to over- or under help individuals with disabilities (Ryan et al. 2006). There are a multitude of negative stereotypes concerning the combination of aging and disability negatively influencing individuals cognitive and physical abilities (Lustig & Cilio, 2017). The intersectionality with gender and disability revealed that there are gender differences in aspects such as mental health for persons with disabilities, with differences being particularly present in the self-construction and use/need for social relationships (Brown, 2014).

4.1.2 Microsystem and Mesosystem

The microsystem is comprised of people that individuals have re-occurrent direct contact with, and formed interpersonal relations (Kaderavek, 2011). Within the current context these systems are encompassing family members or primary caregivers of persons with disabilities. Difficulties in this system can emerge when there is a lack of stability within the relationships between the individuals with disabilities and family members, or if there is bullying or stigma within the immediate environments (Olivier-Pijpers et al., 2020a). The involvement of family members in the daily life of individuals with disabilities can potentially decrease challenging behaviours, assist individuals in thriving, and provide family members with the opportunity to advocate for the specific needs of the individuals with disabilities (Olivier-Pijpers et al., 2020b).

The mesosystem describes the relation and interactions between the different microsystems of individuals (Kaderavek, 2011). Within the chosen context this system is particular essential as evidence outlined the socio-economic disadvantages within the Calabar community, and there suggestively being a lack of resources from the macro- and exosystems that are often compensated by the micro- and mesosystems. Thus, the mesosystem assisting individuals with access to services and resources can minimize barriers for individuals with disabilities, especially if the individuals surrounding provides inter-agency partnerships and efficient interprofessional collaboration (Lindsay et al., 2016). Yet, a lack of communication or coordination between microsystems can also add additional barriers to the daily challenges of individuals with disabilities (Wright et al., 2019).

4.1.3 Exosystem and Macrosystem

The exosystem incorporates external systems whose actions impact the individual while the individual is not directly participating in them, while the macrosystem encompasses cultural values and legal policies of individuals with disabilities (Kaderavek, 2011). Within

Brazil there are different community organizations to provide support for individuals with disabilities, as well as that the law on paper guarantees public health care services called Unified Health System for all citizens (Younger, 2016). These legal opportunities to proper assistive devices and psychological resources can assist individuals with disabilities in daily life. Nevertheless, lack of services or discriminatory policies, such as lack of transportation options to health care service centres for individuals with disabilities, can also exaggerate challenges (United Nations, 2015).

Apart from health care aspects the government also aims to support individuals during their educational and work journey. Thus, another governmental policy to aid social inclusion of individuals with disabilities in the school system, is the closing of all special needs schools, and inclusion of all students with disabilities in the mainstream schools (Marques et al., 2020). In relation to higher education within the Salvador in particular, there are also services available at University of Bahia for university students with disabilities, while the university also has a research collaboration with the Calabar community (Nape, 2023). Additionally, assistances for individuals with disabilities were made on a policy level for individuals that are unable to work. The Cash Benefit program as mentioned above ensures that individuals with disabilities have a constant income, while however arguably benefits provided are too small to ensure proper living (Sabariego, 2017). The outlined opportunities show that exo- and macro level influences have consequences in the micro- and mesosystems of individuals with disabilities.

Reflecting on the Brazilian context social norms, attitudes, and dominant values have to be considered, as they can either promote inclusion and acceptance of individuals with disabilities, or reinforce marginalization and negative stereotypes, as well as demonstrating intersections with aspects such as ethnicity (Kirakosyan, 2021). Aspects such as quotas for individuals with disabilities improve the employment rates of individuals with disabilities, while however a multitude of social constraints and discrimination in the job market remains, especially for more severe functional impairments (De Araujo et al., 2022; Maia & Garcia, 2019). In relation to that there are also intersections between disability and factors such as race, socio-economic status, or gender that increase likelihood of direct and perceived discrimination that influence daily life satisfaction of individuals with disabilities (Rubia & Brian, 2017). Salvador da Bahia, is the self-announced Afro-Capital, inhabiting the highest population of individuals with African descent compared to any other place in the world outside Africa, with approximately 80% of the population identifying as Black (Diakite, 2022). There are higher rates of police violence, wage gaps, and lack of employment of

individuals with African descent. The aim of any research should eventually be to assist in changing and improving support and interventions at the macro-level, whereby that however is often a long-term process, that needs to fully comprehend the issues faced on the baseline (Kirakosyan, 2021).

4.1.4 Chronosystem

The chronosystem refers to the given time context that influences human development, and the relation between the environment and the individual (Kadaravek, 2011). This system has to be considered in order to place the rights and opportunities of individuals with disabilities into the historical context. Thus, research has to take into consideration which cultural shifts are present, what legislations are implemented, and what advancements have been made in regards to aspects such as assistive technology (World Health Organisation, 2022).

Within the Brazilian context, Brazil passed the Statue of People with Disabilities law in 2015 to promote inclusion of individuals with disabilities in all areas of life, as well as that national and international policies are in place to ensure the equal participation of all members of society (United Nations, 2006). However, the last right-wing government made significant cuts on social projects and disability support, which was further influenced by the global COVID-19 pandemic that especially disadvantaged individuals of various minority groups, including individuals with disabilities (Brazilian Transformation Index, 2022; United Nations, 2020). It is therefore essential to take into account that even though the chronosystem can bring positive changes over time, it may also reinforce negative attitudes and patterns about disability if those attitudes are not challenged.

5 Methodology

5.1 Research Methodology

The research sample was strategically chosen to get a holistic view of the current situation and incorporated different groups of participants from Calabar, including individuals with disabilities, their caregivers, and community leaders. Historically, research was primarily undertaken with white men from WEIRD countries, with approximately 80% of research participants even in modern society still coming from WEIRD countries, with research findings often assumed to be generalizable while lacking diversity (Bell & Willis-Wallace, 2021). Including participants that have an intersectionality of various minority groups such as African heritage, females, or low socio-economic status not only enriches research findings but is of utmost importance to draw appropriate conclusions about needs of individuals. To tailor the study only individuals with bodily disabilities were included to avoid confounding factors related to other types of disabilities. Interviews were undertaken in Portuguese, being the official language in Brazil, and later translated to English, as previous research suggests that different biases emerge when interviewing participants in a second language (Akerhust et al., 2018). Using participants native tongue is further important, as research outlined that individuals can express emotions and content more precise and effective in their mother tongue (Pell et al., 2009).

5.2 Data Collection Method and Sources

The researchers conducted semi-structured face-to-face interviews due to the scarcity of knowledge about the situation of individuals with disabilities in the Calabar community and their support systems, giving participants the power to narrate their personal experiences (Opdenakker, 2006). Using face-to-face interviews aids synchronous communication in time and place, whereby using this method is an advantage as researchers can pick up on various social cues such as body language or voice, which improves the comprehension of the verbal answers of participants (Opdenakker, 2006). This method was further strengthened by recording the interviews with the permission of participants, as it ensures the accuracy of the content compared to writing notes. Implementing semi-structured interviews was essential to explore the thoughts of different groups of participants and to cover the major topics of interest about an under-researched area (De Jonckheere & Vaughn, 2019). Topics included challenges of individuals with disabilities in Calabar in daily life. The research was further supported by the use of naturalistic observations and field notes of the researcher.

5.3 Analysis

Thematic analysis was used to analyse the data collected from face-to-face interviews, as previous research suggests that this method is a theoretically flexible and accessible approach to analyse qualitative data (Braun & Clark, 2006). Due to the increase in recognition in qualitative data the importance of analysing data in a consistent and exhaustive manner through systemizing and disclosing the method becomes increasingly important to ensure the credibility of the process (Nowell et al., 2017). The implemented analysis method required several steps including data familiarization, generation of initial codes, searching for themes, revision of themes, and final reporting of defined themes (Guest et al., 2011).

Firstly, the collected interview data was transcribed into Portuguese and English using the internal transcription software Autotekst of the University of Oslo, and translations double checked by the research-tandem partner of the master student, a Portuguese native speaker. Using an internal transcription software was chosen as it limited expenses for funding, need to use transcription equipment, and need for lengthy amount of effort and skill for accurate transcription, while abiding by ethical standards to warrant anonymity (Alcock & Iphofen, 2007). A native speaker from the local context was used to check transcriptions and associated translations to ensure the context is conveyed properly, as meanings can vary across cultural contexts and are socially constructed, which had to be accounted for as the master thesis student has another cultural background (McMullin, 2023). After the transcripts were thoroughly read and re-read to receive a comprehensive understanding of the overall context and content. Secondly, initial codes were generated through identification of themes, concepts, and patterns that were prevalent within the data (Braun & Clarke, 2006). The codes were subsequently reviewed and refined based on the relevance of the given context, taking the regional context into consideration and consulting with the research-tandem member about the codes, and the relevance of codes for the defined research question. Thirdly, codes were grouped into emerging major themes with similar concepts or ideas. Lastly, the emerged themes were reviewed considering their relevance and accuracy for the defined research question and final themes were defined and reported (Braun & Clarke, 2006).

5.4 Ethical Considerations

The current study received NSD (reference number: 965734) approval, as the study was conducted at part of a master thesis project at the Department of Special Needs Education at the University of Oslo. Due to the master thesis being written with data collected in Brazil, as the student participated in the research-tandem with the Federal University of Bahia, data was recorded in Brazil but stored securely on the TSD servers of the University of Oslo. The

student abides by the Norwegian Code of Ethics, due to the associated university affiliation, while taking into consideration the local ethical guidelines, as evidence shows that there can be major cultural differences in ethical aspects when conducting field work, especially in non-Western countries (Honan et al., 2013). To ensure anonymity transcripts were anonymised, and sound recordings stored double password protected at TSD servers, and will be deleted on June 1 after submission of the master thesis.

No incentives were given to ensure participation was based on free choice rather than due to undue inducement, and participants could only participate after given written informed consent (Halpern et al., 2021). Informed consent forms can be found in English and Portuguese for individuals with disabilities (Appendix B) and support systems of individuals with disabilities (Appendix C). As Portuguese is the national language in Brazil, all participants were provided with the Portuguese version of informed consent forms. It was outlined to participants that they can withdraw from the study at any point in time without consequences. Due to the vulnerability of the chosen participant group and particularity of the chosen community interviews were conducted by the Brazilian research tandem partner, who is born and raised in Salvador da Bahia, to account for potential ethical limitations the researcher has due to cultural and societal differences, and language barriers, as field work has to properly adjusted especially in violent and closed contexts (Bliesemann de Guevara & Bøås, 2020).

5.5 Positionality of the Researcher

As a study investigating the challenges faced by individuals with disabilities in Calabar, a low-income community, the authors positionality is majorly shaped through her educational experiences and personal background that she brings to the current study. Having been raised in a middle-class family in Germany, she was privileged to be exposed to a supportive environment and extensive educational opportunities, including the ability to travel to other countries, such as through this research-tandem opportunity between the University of Oslo and the Federal University of Bahia. Through her studies in the Master of Special Needs Education she has gained valuable insight into inclusive practices and the influences of various systems on the quality of life of individuals with disabilities.

Her positionality as an outsider studying a marginalized community with a multitude of intersections of disadvantaging factors allows her to bring a fresh perspective to the research environment (Yanto & Pandin, 2023). However, it is essential to be aware that her previous background and experiences can potentially bias and limit her understanding and interpretation of the challenges faced by the individuals with disabilities in the community.

Yet, through the set-up of the research-tandem being paired with a local student, who has been raised in the local surroundings, was an incredible aid to view interviews to an inside and outside perspective.

Having had the opportunity to study and work across several cultural contexts, aids her recognition of the importance of cultural sensitivity and contextual factors. Therefore, she aimed to approach the current research with an open-mind, trying to understand the complexities and intersections of the given context in the community, while challenging her own pre-conceptions. Through constant reflexivity, she aims to continuously critically reflect and potentially re-evaluate her positionality throughout the research process (Olukotun et al., 2021). Via this study she intends to amplify the voices of the community members, providing the space to let the study be shaped by the narrative of their experiences (Culhane-Pera et al., 2021). Focusing on different groups within the community that have disabilities, or support individuals with disabilities, she aims to ensure that the study and the associated findings are beneficial to the community as a whole, while respecting the differences in viewpoints of various influential groups.

In summary, being aware of her educational privileges and cultural background provides her with an advantage to be vary of differences between her experiences and the lived realities of individuals within the community. By acknowledging her positionality and the associated potential pre-conceptions and biases she may bring into the research, she aims to conduct the research on challenges of persons with disabilities in this marginalized community in an ethical, holistic, and inclusive manner, and provide applicable and culturally appropriate potential solutions.

6 Results and Discussion

The current study aimed to explore the challenges faced by persons with disabilities in the Brazilian Calabar community in everyday life and the impact of the different ecological systems. During the semi-structured face-to-face interviews with participants four major themes emerged based on the research question, with the codes for each of the major themes being available in Appendix D. The first theme regarded access challenges individuals with disabilities faced, with significant issues arising from difficulties accessing transportation, public spaces, and buildings due to inadequate or non-existent accommodations. Figure 1 demonstrate the entrance to the community library including several steps, reportedly difficult for individuals with bodily disabilities, limiting accessibility. Similarly, Figure 2 and 3 show the staircases within the streets and house entrances in the Calabar community, majorly restricting physical accessibility. The second theme was the intersectionality between disability and poverty. Participants outlined that individuals with disabilities are living in lower socio-economic situations in Calabar and face financial insecurity due to limited access to employment and shortcomings of social service support. The third theme was the intersection of disability and discrimination, with participants stating that they have experienced discrimination due to their disabilities, and were also discriminated based on aspects such as ethnicity. The fourth theme was the importance of support systems for individuals with disabilities, with individuals highlighting the importance of supportive networks, specifically family. The following short discussion will highlight some of the complex interactions between individual and contextual factors of the ecological system that restrict individuals with disabilities in the chosen community in everyday situations based on the emerged themes, outlining the intersectionality of disability with other factors.

Figure 1

Community library entrance in Calabar da Bahia



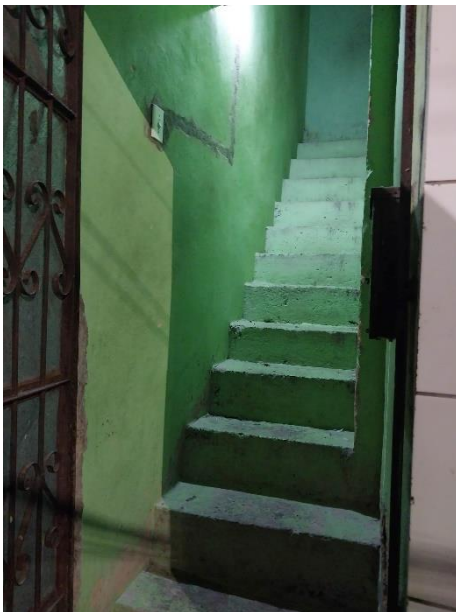
Figure 2

Streets in the community of Calabar da Bahia.



Figure 3

House entrance in Calabar da Bahia



Considering theme 1, access challenges for individuals with disabilities have been a longstanding issue worldwide, with governmental institutions having made efforts to address issues (United Nations, 2006). Accessibility for all members of society is a major implication of the study, as not only persons with disabilities, but also an increasingly aging worldwide population will require accommodations in their surroundings to provide equal access (National Institute of Health, 2023; The World Bank, 2023). Universal design principles are therefore required, which should be developed through collaborations between designers, policymakers, and disability advocates, as the current study points out that different groups

within the community might have different views about challenges, essential to consider for a holistic view (Erdtman et al., 2021). Specifically, in Calabar state level interventions need to be implemented to strengthen infrastructure and ensure access to the community for everyone, rather than focusing disability research primarily on individual barriers (Saran et al., 2023). Additionally, advances in assistive technology could be an implication of the study as mobility aids can mitigate challenges of individuals with disabilities if they are financially affordable and adapted for the given environment (World Health Organisation, 2022). However, within Calabar physical access would have to be addressed through macro- and exo-level interventions prior to implementing these solutions as interviews outlined that for several areas access to only mobility aids did not ensure access to the neighbourhood. Thus, in-house treatments such as physiotherapy or organized transports such as to doctors could be practical solutions to implement on a micro- and meso-level to at least partially account for the lack of access, until more long-term solutions can be found. This aspect is particularly essential, as even though community members outlined that they support each other through internal networks, it was impossible for them to completely account for the lack of physical access.

In relation to the intersectionality between disability and poverty, this complex issues has different implications. Individuals with disability face numerous barriers within the job market, often resulting in dependence in financial insecurity and dependence on social services, which have additional short comings in themselves (Dag & Kullberg, 2016). Concentrated efforts have to ensure availability of job opportunities and accommodate workplaces, to include individuals with disabilities in the workforce and provide possibilities to thrive. Previous projects in the community provided women that suffered domestic violence with movable stands to sell sausages and sweets in order to gain their own income independently, with projects like these potentially being an opportunity to include individuals with disabilities. Another project in a low-income community produced different art by individuals with disabilities, which was sold to generate a partial income (Soliman, 2021). Workshops are in place for elderly organized by the library staff to participate in artistic projects, which could similarly be done for individuals with disabilities. Strategies like these are essential to not only improve financial disadvantages but increase participation in society and increase self-confidence. Considering shortcomings of social services is essential in relation to the intersectionality of poverty and disability, as lack of adequate support for individuals needs can drastically impair independency in daily life of individuals with disabilities (Brazilian Transformation Index, 2022). In Brazil specifically due to the cuts in

social services due to the previous government, additional investments in adequately funded and staffed social services are required to tailor to the needs of individuals with disabilities. In relation to both aspects, the caregivers role also has to be taken into consideration. Family members were often full-time caregivers of individuals with disabilities, and therefore lacked job opportunities, being either unemployed or only part-time employed, while the role itself implies various additional stressors (Ae-Ngibise et al., 2015). They were therefore double disadvantaged as they did not receive any compensation for their caregiving role, while also not being eligible for financial support through the state if they did not generate an income.

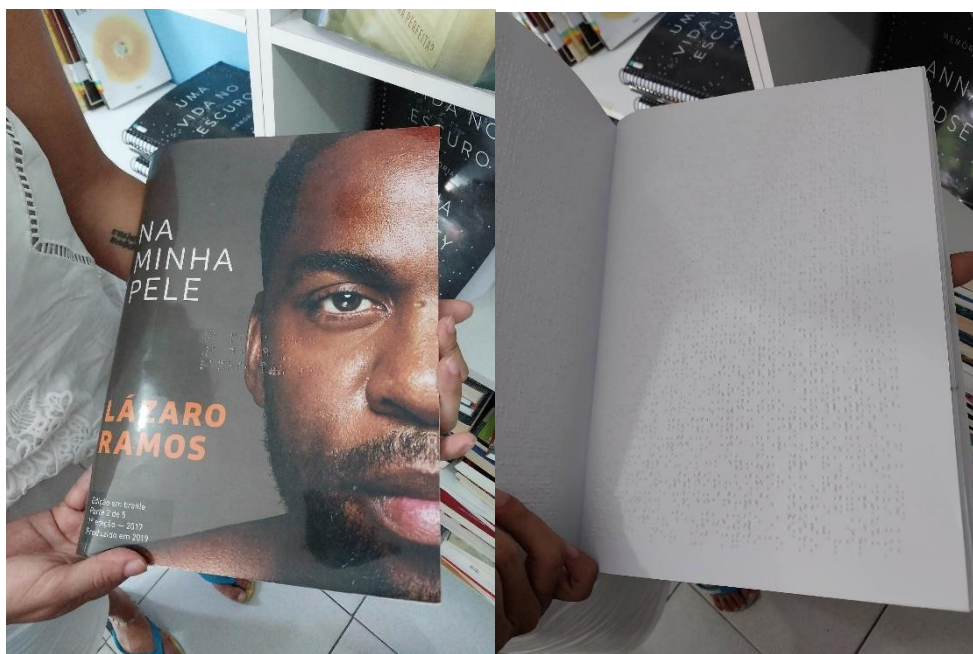
Theme three outlined the intersection between disability and discrimination, with especially aspects such as racism compounding already faced discriminatory issues based on disability for individuals, resulting in increased exclusion and marginalisation. Multiple marginalized groups often face unique challenges, that are often not considered in literature, with these complex interactions being essential to address to ensure equal rights and opportunities for all members of society (Watermeyer, 2017). Literature often disregards intersections such as being a wheelchair user, being from African descent, being female, being elderly, and living in a low socio-economic environment, instead considering that a Western individual in a wheelchair has the same challenges and generalizing results globally, that might not necessarily be generalizable. Thus, there could be an implementation of support groups for individuals with disabilities and family members of individuals with disabilities, or training programs about how to best support different kinds of disabilities (Regy et al., 2022). This would not only assist family members to better support individuals with disability in the microsystems, but also raise awareness within the community on an exo- and macro-level, decreasing stereotyping and discrimination of various disabilities, and disability in general, with stigma reduction being an under-researched part of aspects that drive exclusion of individuals with disabilities (Saran et al., 2023).

The fourth theme that emerged highlights the crucial role of support systems for individuals with disabilities. Support systems were crucial for all persons with disabilities regardless if they were family or community-based, highlighting the importance of facilitating those networks. Thus, it is essential to improve the communication among those networks, as within interviews participants outlined that different networks often function separately. A suggestion could be that the different microsystems have combined focus groups to address arising needs of individuals with disabilities across the community on a constant basis (Blaizot et al., 2017).

Issues arose for individuals with visual problems that could not use resources such as braille books available in the library as shown in Figure 4, as they never learned to read them, reading sessions could be made available that individuals could attend, or singing session to use more vocal aspects, strengthening community exposure, social inclusion, and participation in daily life (McFerran et al., 2022). To improve community belonging potential community festivals or dinners could be organized to expose individuals with disabilities to community life, they are currently often separated from, while raising awareness and increasing exposure to disability among other community members. Previous evidence suggests that exposure can drastically decrease stereotypes and prejudice and increase willingness to help (Babik & Gardner, 2021). The military police also organises different sport activities for children, which could be adapted to also suit the needs of individuals with disabilities, providing opportunities for interaction through physical education, which has been shown to increase belonging (Kiuppis, 2018). It would be useful to implement any of the suggested projects that the state provides funding or paid staff to organize those project. Previous initiatives in Europe matched teenagers with elderly to reduce social isolation and improve understanding, which could be transferred matching impoverished teenagers or women that suffered from violence from the community with individual with disabilities, providing support for one another (O'Brien, 2019). Regarding this aspect formal and informal support should also be put in place for caregivers, as caring can be a highly demanding role adding increased stressors on individuals (Ae-Ngibise et al., 2015).

Figure 4

Braille books from the community library in Calabar da Bahia



6.1 Strengths and Weaknesses

A major strength of the study is that the interviews include both individuals with disabilities and their support systems, providing a holistic approach that encompasses views from different angles. Further including two individuals using a wheelchair and another individual with a visual disability, with two individuals identifying as male and one as female, presents a variety of bodily disabilities and genders. Researching within Calabar as a community that has a lot of intersections between race, low socio-economic status, disability, and gender also increases the value of the research findings outlining how individuals are often disadvantaged due to several factors and that these factors can accumulate (Treuke, 2019a). The sample is also majority female which is representative of the strong female presence in leadership in the Calabar community.

Conducting face-to-face interviews further allowed for more empathetic connections with participants, and provided the opportunity for clarification of questions and the chance to explain the context (Opdenakker, 2006). Interviews being conducted by a local research-tandem partner, born and raised in Salvador, assisted by the researcher from Europe enriched the perspectives of the research due to being able to provide insider and outsider perspectives. Using interviews, naturalistic observations, and field notes in combination enriched the transparency and trustworthiness of the current study (Mulhall, 2003).

The use of different participant groups increased potential variability of answers, however due to the lack of research on the topic in general and in specific in the given context of Calabar the researcher deemed the benefits of having a broad overview of the challenges as outweighing the cost of variability. Additionally, having a main researcher that is not fluent in Portuguese, could be considered a limitation, which however was accounted for by the assistance of a research-tandem partner that was a native Brazilian, who conducted the interviews in the presence of the researcher. Having only individuals identifying as female as caregivers or community representatives could potentially make the findings biased. Yet, due to years of historic male dominance in the community, and a current rise of female empowerment, having a majority female perspective might shed light on previously non-considered views. Face-to-face interviews potentially make participants feel uncomfortable, whereby this was partially adjusted for by conducting interviews at a location and time of the participants choosing (Dempsey et al., 2016).

6.2 Future Research

This study focused on a holistic view of disabilities within the Calabar community incorporating different viewpoints of individuals with disabilities, primary caregivers, and

community leaders, with there being a need to focus future research more narrowly on specific disabilities. Future studies should examine the needs of particular disabilities such as wheelchair users and individuals with visual impairment separately, and investigate the needs of caregivers. Intersections with disability such as age, gender, and ethnicity should be further researched, rather than basing research on the assumption that individuals with the same disability have the same needs or resources at their disposal (Jones, 2010). The discrepancy between a universal health care system in theory and the lack of access to individuals in reality should also be investigated to address shortcomings more effectively and uphold the national and international right of people with disability.

Research should also test interventions that focus on disability support, as within the Calabar community interventions for children and women suffering from domestic-violence reached promising results. Providing opportunities for individuals with disabilities to be productive members of the workforce and community, can drastically improve overall quality of life (Altman, 2017). Findings showed that some resources were available for individuals with disability such as braille books, however, there is a need for interventions to teach braille to individuals with visual impairment, as the participant of this study could not use the implemented resources.

7 Conclusion

The study investigates challenges of individuals with disabilities in the Calabar community through an ecological framework using semi-structured face-to-face interviews. Findings outline that the main challenge for individuals with disabilities is different forms of access, particularly physical access to buildings and surroundings. It outlines the need for future research in the area regarding individuals with different disabilities within the community, and the necessity for interventions from the state-level to improve access for individuals with disabilities to the community and the city of Salvador as a whole. Results also outline the influence of different intersections with disability that need to be considered such as poverty and discrimination specifically in relation to ethnicity. Furthermore, the importance of support systems for individuals with disabilities, particularly informal support systems such as family accounting for exo- and macro level shortcomings is highlighted.

The project however not only has implications based on the findings of the study itself but also the unique research set-up. Providing the opportunity to students to be part of a research tandem increases sensitivity and awareness to different cultural context through a lived experience filled with emotional and personal memories that can have large personal impacts. It is suggested to extend on these tandem opportunities and research the impact on students, as it will influence cultural awareness across researchers and the bi-directional influence of researchers and participants on one another.

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Appendix A

Author Guidelines

The *Journal of International Special Needs Education* (JISNE) is a multi-disciplinary journal of Division of International Special Education and Services (DISES), a division of the Council for Exceptional Children (CEC). JISNE publishes original research and theoretical contributions concerning disability and the delivery of special education programs and services to individuals with disabilities throughout the world. JISNE readers are typically DISES members and members of the international scientific community who are interested in information related to the field of special education around the world. Readers represent a broad range of geographic, ethnic, cultural, and language backgrounds, who are interested in diverse research perspectives.

Aims and Scope

JISNE considers a variety of manuscripts for publication. All manuscripts should present an international perspective and include implications for research, policy, or practice for global readers. Submissions must fall into one of the following categories:

- **Research articles:** Original research articles report on data collected through established research methods. Manuscripts reporting on original research should focus on individuals with disabilities. Examples of acceptable research methods include group, single subject design, quantitative studies, qualitative studies, and mixed methods designs. Research manuscripts must include a fully developed methods section and clear implications for practice.
- **Literature reviews:** Reviews of the literature, meta-analyses, and syntheses of the literature that expand the understanding of exceptionality and special education practices on a global level. Literature reviews must include clear implications for practice.
- **Position and policy papers:** Manuscripts that address international disability policy and/or inform the theoretical discussion of special education and the understanding of exceptionality on a global level.
- **Case studies:** Case studies outlining interesting local initiatives or comparative studies that readers can generalize to historical, social and global trends. These papers should include information regarding generalization and implications related to other settings.

How to Submit

Before submitting your manuscript, please ensure you have carefully read and adhere to our [Author Guidelines](#). Manuscripts not conforming to these guidelines or not aligning with the aims and scope of *JISNE* will be rejected.

Please submit articles via email to jisne@dises-cec.org for pre-screening. Authors with manuscripts that meet the requirements outlined in the [Author Guidelines](#) will then be sent a link to our submission portal.

JISNE does not charge authors a publication fee.

Manuscript Requirements

Manuscripts submitted to *JISNE* should conform to APA format (see Publication Manual of the American Psychological Association, 7th Edition, 2010). *JISNE* only considers manuscripts written in English that have not been published or are being considered for publication by another journal. Your manuscript narrative should ideally be between 15 and 20 double spaced pages, with the entire manuscript no more than 30 pages including abstract, references, figures, and tables. Rationale for a longer manuscript may be considered. An abstract must be included, and should be between 150 and 250 words in length.

Authors should include a brief description of disability definition, political and civic systems, and any other relevant issues in the country of origin, and not assume all readers have the contextual understanding or knowledge. Manuscripts should also avoid bias in language. When referring to individuals with exceptionalities, use people first language. People first language places the person before the disability (e.g. “child with a learning disability” rather than “learning disabled”) and avoids language that victimizes or sensationalizes disability (e.g., “suffers from autism,” or “is wheelchair-bound”).

JISNE recognizes that in seeking submissions from the international community, submissions will come from authors for whom English is a second language and who may not be familiar with APA 7th edition formatting. Authors for whom English is a Second Language, it is highly recommended that a colleague or copy editor, who is fluent in English, review the manuscript before submission. If a manuscript’s content is strong, *JISNE* editors may work with the authors to prepare it for publication.

Submitted manuscripts should adhere to the following guidelines for APA 7th edition formatting. These include, but are not limited to:

- Manuscript is double spaced with 1-inch margins (Times Roman size 12 font type preferred).
- All pages are numbered in sequence, starting with the title page. *Note:* The uploaded manuscript should include a title page and abstract but you must remove the author(s) name and other identifying information from the manuscript due to the blind review process.
- Key words and a running head are included in the appropriate places
- Titles and headings are bold and in the appropriate location within the manuscript.
- Tables are double-spaced and formatted using Word functions.
- Digital object identifiers (dois) are included in the reference list.
- Use tab for indent (not spaces)
- Text are *left justified*
- The use of visual representations (tables and figures) should be used when necessary to assist communication. For guidance, see: <https://apastyle.apa.org/style-grammar-guidelines/tables-figures/>
- All tables and figures are presented at the end of the manuscript, after the list of references.

There are many resources available online to those needing support with APA guidelines. These resources can help answer questions about APA formatting and style.

APA Style FAQ: <https://apastyle.apa.org/style-grammar-guidelines/>

APA Sample Paper: <https://apastyle.apa.org/style-grammar-guidelines/paper-format/sample-papers>

Ethics

In their cover letter, authors must include an explanation of any conflict of interest that may exist, and if any work contained in the manuscript has been submitted or published elsewhere and how this does or does not constitute dual publication. When using human subjects, authors must describe how the study design protects the participants (e.g., institutional ethics review board).

JISNE's Publication Ethics and Malpractice Statement can be found [here](#). This statement includes additional information related to the following topics: Authorship and Author Responsibilities, Peer Review Process, Publication Ethics, Copyright and Access, Archiving, Ownership and Management, and Publication Schedule.

Peer review Policy

JISNE manuscript reviews are double-blind; authors and reviewers are anonymous. Once submitted, a manuscript is screened by the Editor to determine if it meets the manuscript requirements of *JISNE*. Authors may request or object to specific reviewers they feel may be biased. The editorial board will attempt to accommodate these requests, but does not guarantee such honor.

Permissions

Authors are responsible for ensuring compliance with intellectual property laws. Permission for publication must be obtained for any copyrighted material used in a manuscript.

File Types

JISNE only accepts manuscripts in Word DOC or RTF formats.

Corresponding Author Contact Details

Email, mailing address, telephone number, and academic affiliations for all authors must be provided, separately from the main text of the manuscript.

Further Information

Any correspondence, queries, or additional requests should be sent to jisne@dises-cec.org

Appendix B

Informed Consent for Individuals with Disabilities

Are you interested in taking part in the research project ” Support systems for individuals with disability in Calabar”

This is an inquiry about participation in a research project where the main purpose is to learn more about the different support systems of individuals with disability in Calabar. In this letter we will give you information about the purpose of the project and what your participation will involve.

Purpose of the project

This open-ended interview is part of a master's degree project in special needs education at the University of Oslo. It deals with challenges individuals with disability in Calabar face in their daily lives and support systems they use.

Who is responsible for the research project?

The University of Oslo is the institution responsible for the project, while the project is part of a research tandem project with UFBA.

Why are you being asked to participate?

As an individual with disability living in the Calabar community you are invited to participate in this research as we would like to learn more about your experience and insight of the topic.

What does participation involve for you?

If you chose to take part in the project, this will involve that you participate in an open-ended interview. It will take approx. 20-45 minutes. The interview includes questions about (Your daily life in the community, challenges you encounter, and support systems you use). Your answers will be audio-recorded.

Participation is voluntary

Participation in the project is voluntary. If you chose to participate, you can withdraw your consent at any time without giving a reason. All information about you will then be made anonymous. There will be no negative consequences for you if you chose not to participate or later decide to withdraw.

Your personal privacy – how we will store and use your personal data

We will only use your personal data for the purpose(s) specified in this information letter. We will process your personal data confidentially and in accordance with data protection legislation (the General Data Protection Regulation and Personal Data Act).

- The student, the research-tandem partner of the student, and supervisor will have access to personal data.
- I will replace your name and contact details with a code. The list of names, contact details and respective codes will be stored separately from the rest of the collected data. The audio recordings will be stored on Nettskjema Diktafonapp.
- The data will be collected in Brazil but stored through the secured services for sensitive data of the University of Oslo.

Also, participants will remain anonymous in any research reports or papers.

What will happen to your personal data at the end of the research project?

The project is scheduled to end in June 2023. Audio-recordings will be deleted after the end of the project and all data will be anonymised

Your rights

So long as you can be identified in the collected data, you have the right to:

- access the personal data that is being processed about you
- request that your personal data is deleted
- request that incorrect personal data about you is corrected/rectified
- receive a copy of your personal data (data portability), and
- send a complaint to the Data Protection Officer or The Norwegian Data Protection Authority regarding the processing of your personal data

What gives us the right to process your personal data?

We will process your personal data based on your consent.

Based on an agreement with the University of Oslo Data Protection Services has assessed that the processing of personal data in this project is in accordance with data protection legislation.

Where can I find out more?

If you have questions about the project, or want to exercise your rights, contact:

- *The University of Oslo* via Marilena Juettemeier (student; marilenj@student.uv.uio.no) or Luca Tateo (supervisor; luca.tateo@isp.uio.no)
- Our Data Protection Officer: (Marika Vartun; marika.vartun@isp.uio.no)
- Data Protection Services, by email: (personverntjenester@sikt.no) or by telephone: +47 53 21 15 00.

Yours sincerely,

Luca Tateo

Marilena Juettemeier

Project Leader
(Researcher/supervisor)

Student

Consent form

I have received and understood information about the project ‘Support systems for individuals with disability in Calabar’ and have been given the opportunity to ask questions. I give consent:

- to participate in an open-ended interview

I give consent for my personal data to be processed until the end date of the project, approx. 01 June 2023

(Signed by participant, date)

Você está interessado/a em participar do projeto de pesquisa

“Sistemas de apoio a pessoas com deficiência em Calabar”

Esta é uma carta/termo de consentimento sobre a sua participação em um projeto de pesquisa cujo objetivo principal é conhecer os diferentes sistemas de apoio às pessoas com deficiência em Calabar. Neste termo, daremos informações sobre o objetivo do projeto e o que a sua participação envolverá.

Objetivo do projeto

Esta entrevista aberta faz parte de um projeto de mestrado em educação especial na Universidade de Oslo. O projeto quer compreender quais são os desafios que as pessoas com deficiência em Calabar enfrentam em suas vidas diárias e nos sistemas de apoio que usam.

Quem é o responsável pelo projeto de pesquisa?

A Universidade de Oslo é a instituição responsável pelo projeto, enquanto o projeto faz parte de um projeto conjunto de pesquisa com a UFBA.

Por que você está sendo convidado a participar?

Como pessoa com deficiência que vive na comunidade de Calabar, você está convidado a participar desta pesquisa, pois gostaríamos de saber mais sobre sua experiência e visão sobre o assunto.

O que a participação envolve para você?

Se você optar por participar do projeto, isso envolverá sua participação em uma entrevista aberta. Levará aprox. 20-45 minutos. A entrevista inclui perguntas sobre (Sua vida diária na comunidade, desafios que você encontra e sistemas de apoio que você usa). Suas respostas serão gravadas em áudio.

A participação é voluntária

A participação no projeto é voluntária. Se você escolheu participar, você pode retirar seu consentimento a qualquer momento, sem dar um motivo. Todas as informações sobre você serão tornadas anônimas. Não haverá consequências negativas para você se optar por não participar ou, posteriormente, decidir desistir.

Sua privacidade pessoal – como armazenaremos e usaremos seus dados pessoais

Usaremos seus dados pessoais apenas para a(s) finalidade(s) especificada(s) nesta carta informativa. Processaremos seus dados pessoais de forma confidencial e de acordo com a legislação de proteção de dados (Regulamento Geral de Proteção de Dados e Lei de Dados Pessoais).

- O/A aluno/a, o/a parceiro de pesquisa do/a aluno/a e o orientador terão acesso aos dados pessoais.
- Substituirei seu nome e detalhes de contato por um código. A lista de nomes, contatos e respectivos códigos serão armazenados separadamente dos restantes dados recolhidos. As gravações de áudio serão armazenadas no Nettskjema Diktafonapp.
- Os dados serão coletados no Brasil, mas armazenados por meio dos serviços seguros para dados confidenciais da Universidade de Oslo.

Além disso, os participantes permanecerão anônimos em quaisquer relatórios ou artigos de pesquisa.

O que acontecerá com seus dados pessoais ao final do projeto de pesquisa?

O projeto está programado para terminar em junho de 2023. As gravações de áudio serão excluídas após o término do projeto e todos os dados serão anonimizados

Seus direitos

Desde que possa ser identificado nos dados recolhidos, tem o direito de:

- acessar aos dados pessoais que estão a ser escritos sobre si
- solicitar que seus dados pessoais sejam excluídos
- solicitar que dados pessoais incorretos sobre você sejam corrigidos/retificados
- receber uma cópia dos seus dados pessoais (portabilidade de dados), e
- enviar uma reclamação ao Diretor de Proteção de Dados ou à Autoridade Norueguesa de Proteção de Dados sobre o processamento de seus dados pessoais

O que nos dá o direito de processar seus dados pessoais?

Processaremos os seus dados pessoais com base no seu consentimento.

Com base em um acordo com os Serviços de Proteção de Dados da Universidade de Oslo, a mesma avaliou que o processamento de dados pessoais neste projeto está de acordo com a legislação de proteção de dados.

Onde posso saber mais?

Se você tiver dúvidas sobre o projeto ou quiser exercer seus direitos, entre em contato:

- A Universidade de Oslo através de Marilena Juettemeier (estudante; marilenj@student.uv.uio.no) ou Luca Tateo (supervisor; luca.tateo@isp.uio.no)
- Nosso Diretor de Proteção de Dados: (Marika Vartun; marika.vartun@isp.uio.no)
- Serviços de Proteção de Dados, por e-mail: (personvertjenester@sikt.no) ou por telefone: +47 53 21 15 00.

Com os melhores cumprimentos,

Luca Tateo

Marilena Juettemeier

Líder do projeto
(Pesquisador/supervisor)

Aluna

Formulário de consentimento

Recebi e compreendi informações sobre o projeto ‘Sistemas de apoio para pessoas com deficiência em Calabar’ e tive a oportunidade de fazer perguntas. Eu dou consentimento:

- participar de uma entrevista aberta

Dou consentimento para que os meus dados pessoais sejam tratados até à data final do projeto, aprox. 01 de junho de 2023

(Assinado pelo participante, data)

Appendix C

Informed Consent for Support Systems of Individuals with Disabilities

Are you interested in taking part in the research project

”Support systems for individuals with disability in Calabar”

This is an inquiry about participation in a research project where the main purpose is to learn more about the different support systems of individuals with disability in Calabar. In this letter we will give you information about the purpose of the project and what your participation will involve.

Purpose of the project

This open-ended interview is part of a master’s degree project in special needs education at the University of Oslo. It deals with challenges individuals with disability in Calabar face in their daily lives and support systems they use.

Who is responsible for the research project?

The University of Oslo is the institution responsible for the project, while the project is part of a research tandem project with UFBA.

Why are you being asked to participate?

As part of the support system of individuals with disability in the community you are invited to participate in this research.

What does participation involve for you?

If you chose to take part in the project, this will involve that you participate in an open-ended interview. It will take approx. 20-45 minutes. The interview includes questions about (Challenges of individuals with disability and how you assist in supporting individuals). Your answers will be audio-recorded.

Participation is voluntary

Participation in the project is voluntary. If you chose to participate, you can withdraw your consent at any time without giving a reason. All information about you will then be made anonymous. There will be no negative consequences for you if you chose not to participate or later decide to withdraw.

Your personal privacy – how we will store and use your personal data

We will only use your personal data for the purpose(s) specified in this information letter. We will process your personal data confidentially and in accordance with data protection legislation (the General Data Protection Regulation and Personal Data Act).

- The student, the research-tandem partner of the student, and supervisor will have access to personal data.

- I will replace your name and contact details with a code. The list of names, contact details and respective codes will be stored separately from the rest of the collected data. The audio recordings will be stored on Nettskjema Diktafonapp.
- The data will be collected in Brazil but stored through the secured services for sensitive data of the University of Oslo.

Also, participants will remain anonymous in any research reports or papers.

What will happen to your personal data at the end of the research project?

The project is scheduled to end in June 2023. Audio-recordings will be deleted after the end of the project and all data will be anonymised

Your rights

So long as you can be identified in the collected data, you have the right to:

- access the personal data that is being processed about you
- request that your personal data is deleted
- request that incorrect personal data about you is corrected/rectified
- receive a copy of your personal data (data portability), and
- send a complaint to the Data Protection Officer or The Norwegian Data Protection Authority regarding the processing of your personal data

What gives us the right to process your personal data?

We will process your personal data based on your consent.

Based on an agreement with the University of Oslo Data Protection Services has assessed that the processing of personal data in this project is in accordance with data protection legislation.

Where can I find out more?

If you have questions about the project, or want to exercise your rights, contact:

- *The University of Oslo* via Marilena Juettemeier (student; marilenj@student.uv.uio.no) or Luca Tateo (supervisor; luca.tateo@isp.uio.no)
- Our Data Protection Officer: (Marika Vartun; marika.vartun@isp.uio.no)
- Data Protection Services, by email: (personverntjenester@sikt.no) or by telephone: +47 53 21 15 00.

Yours sincerely,

Luca Tateo

Marilena Juettemeier

Project Leader
(Researcher/supervisor)

Student

Consent form

I have received and understood information about the project ‘Support systems for individuals with disability in Calabar’ and have been given the opportunity to ask questions. I give consent:

- to participate in an open-ended interview

I give consent for my personal data to be processed until the end date of the project, approx. 01 June 2023

(Signed by participant, date)

Você está interessado/a em participar do projeto de pesquisa

“Sistemas de apoio a pessoas com deficiência em Calabar”

Esta é uma carta/termo de consentimento sobre a participação em um projeto de pesquisa cujo objetivo principal é conhecer os diferentes sistemas de apoio às pessoas com deficiência em Calabar. Nesta carta, daremos informações sobre o objetivo do projeto e o que sua participação envolverá.

Objetivo do projeto

Esta entrevista aberta faz parte de um projeto de mestrado em educação especial na Universidade de Oslo. O projeto quer compreender os desafios que as pessoas com deficiência em Calabar enfrentam em suas vidas diárias e nos sistemas de apoio que usam.

Quem é o responsável pelo projeto de pesquisa?

A Universidade de Oslo é a instituição responsável pelo projeto, enquanto o projeto faz parte de um projeto conjunto de pesquisa com a UFBA.

Por que você está sendo convidado a participar?

Como parte do sistema de apoio a pessoas com deficiência na comunidade, você está convidado a participar desta pesquisa.

O que a participação envolve para você?

Se você optar por participar do projeto, isso envolverá sua participação em uma entrevista aberta. Levará aprox. 20-45 minutos. A entrevista inclui perguntas sobre (Desafios das pessoas com deficiência e como você auxilia no apoio às pessoas). Suas respostas serão gravadas em áudio.

A participação é voluntária

A participação no projeto é voluntária. Se você escolheu participar, você pode retirar seu consentimento a qualquer momento, sem dar um motivo. Todas as informações sobre você serão tornadas anônimas. Não haverá consequências negativas para você se optar por não participar ou, posteriormente, decidir desistir.

Sua privacidade pessoal – como armazenaremos e usaremos seus dados pessoais

Usaremos seus dados pessoais apenas para a(s) finalidade(s) especificada(s) nesta carta informativa. Processaremos seus dados pessoais de forma confidencial e de acordo com a legislação de proteção de dados (Regulamento Geral de Proteção de Dados e Lei de Dados Pessoais).

- O/A alun/a, o/aparceiro/a de pesquisa do/a aluno/a e o orientador terão acesso aos dados pessoais.
- Substituirei seu nome e detalhes de contato por um código. A lista de nomes, contactos e respectivos códigos serão armazenados separadamente dos restantes dados recolhidos. As gravações de áudio serão armazenadas no Nettskjema Diktafonapp.
- Os dados serão coletados no Brasil, mas armazenados por meio dos serviços seguros para dados confidenciais da Universidade de Oslo.

Além disso, os participantes permanecerão anônimos em quaisquer relatórios ou artigos de pesquisa.

O que acontecerá com seus dados pessoais ao final do projeto de pesquisa?

O projeto está programado para terminar em junho de 2023. As gravações de áudio serão excluídas após o término do projeto e todos os dados serão anonimizados

Seus direitos

Desde que possa ser identificado nos dados recolhidos, tem o direito de:

- acessar os dados pessoais que estão a ser escritos sobre si
- solicitar que seus dados pessoais sejam excluídos
- solicitar que dados pessoais incorretos sobre você sejam corrigidos/retificados
- receber uma cópia dos seus dados pessoais (portabilidade de dados), e
- enviar uma reclamação ao Diretor de Proteção de Dados ou à Autoridade Norueguesa de Proteção de Dados sobre o processamento de seus dados pessoais

O que nos dá o direito de processar seus dados pessoais?

Processaremos os seus dados pessoais com base no seu consentimento.

Com base em um acordo com os Serviços de Proteção de Dados da Universidade de Oslo, avaliou que o processamento de dados pessoais neste projeto está de acordo com a legislação de proteção de dados.

Onde posso saber mais?

Se você tiver dúvidas sobre o projeto ou quiser exercer seus direitos, entre em contato:

- A Universidade de Oslo através de Marilena Juettemeier (estudante; marilenj@student.uv.uio.no) ou Luca Tateo (supervisor; luca.tateo@isp.uio.no)
- Nosso Diretor de Proteção de Dados: (Marika Vartun; marika.vartun@isp.uio.no)
- Serviços de Proteção de Dados, por e-mail: (personvertjenester@sikt.no) ou por telefone: +47 53 21 15 00.

Com os melhores cumprimentos,

Luca Tateo

Marilena Juettemeier

Líder do projeto
(Pesquisador/supervisor)

Aluna

Formulário de consentimento

Recebi e compreendi informações sobre o projeto ‘Sistemas de apoio para pessoas com deficiência em Calabar’ e tive a oportunidade de fazer perguntas. Eu dou consentimento:

- participar de uma entrevista aberta

Dou consentimento para que os meus dados pessoais sejam tratados até à data final do projeto, aprox. 01 de junho de 2023

(Assinado pelo participante, data)

Appendix D
Codes within the Major Themes

Code	Definition	Example
Accessibility		
-financial	Participants describe a struggle in regard to financial aspects in every life	<i>The buses...Right now we took one. The height was huge for her to climb. I had to lift her and I don't even know if I have the money to pay the car instead.</i>
-healthcare	Participants outline challenges to access required healthcare	<i>The doctor we tried for her to receive the support of physiotherapy for that disability. He refused to give her a prescription.</i>
-physical	Participants outline struggles to physically access the community or buildings	<i>We also have the concern of giving accessibility to people in the library, improve this entrance to the bathroom, but the spaces are very small.</i>
- transportation	Participants state issues with usage and/or access to transportation	<i>The buses...Right now we took one. The height was huge for her to climb. I had to lift her.</i>
-autonomy	Participants explain hindrances to living an autonomous life	<i>When we go to the doctor, we stop down there in the dressing room, I have to go with her.</i>
-information	Participants outline struggles or unawareness about information	<i>I did not have access to information. So it was very difficult.</i>
Poverty		
-lack of access to basic needs	Participants describe that they have/had a lack of access due to poverty	<i>During this period of this Bolsonaro government, I was hungry.</i>
-inadequate education	Participants outline that due to poverty	<i>Until he was 15 years old school was</i>

	they did not have as much quality and/or quantity of education as they were entitled to	<i>attended and then it stopped. The problem comes from the broken wheelchair.</i>
-Poor health	Participants state that poverty affected their health outcomes	<i>I washed a lot of clothes, made clothes, and we used burned coal to set fire to be able to light an iron. The temperature of that made my eyes sick.</i>
- Gang violence	Participants state that they experienced or are afraid of gang violence in the neighbourhood	<i>I'm not going to their house, I'm afraid to go there, I could go with her, but I'm afraid. (...)In the event of a shot or a robbery.</i>
Discrimination		
-discrimination and stereotyping	Participants state that they faced discrimination or stereotyping	<i>What we had was a violence generated by the state. The state always ends up violating, these vulnerable communities.</i>
-segregation	Participants outline segregation to other neighbouring communities	<i>Both in the neighbourhood prefectures area and in the health area. The district that comprises this area here is the district Barra and Rio Vermelho, in the health area. Health care works there but not here.</i>
Support systems	Participants state that they used/ are used as support systems for a faced challenge	<i>The difficulty she has, it is just one of them. She walks and falls. When I'm with her on the street, she holds on to me, she squeezes me.</i>

Challenges of Persons with Disabilities in the “Calabar” Community of Salvador da Bahia

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Author Note

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Abstract

The current study aims to provide a comprehensive understanding of the challenges of individuals with disabilities experienced in Calabar da Bahia, Salvador da Bahia, Brazil. Implementing purposeful sampling of three individuals with disabilities and associated support systems, including two primary caregivers and three community leaders, allows for a holistic perspective of experiences. Using ecological theory allows for examination of various influential systems and their impact on the experiences of persons with disabilities. Considering the complexity of the individual and surrounding systems aims to shed light on the multi-dimensionality of challenges. Data was collected through semi-structured interviews and analysed with thematic analysis with four emerging themes; accessibility, poverty, discrimination, and informal support systems, outlining physical accessibility as the most limiting challenge. Results demonstrate that individuals with disabilities experienced major challenges across various ecological influential systems, and that these systems relate to each other through the issues crossing the borders of the different ecological environments. Future research should investigate how to improve physical accessibility in the community, and further evaluate needs of various groups of disabilities in the community.

Keywords: persons with disabilities, Calabar, Brazil, ecological theory, challenges

Challenges of Persons with Disabilities in the "Calabar" Community of Salvador da Bahia

Modern society in Brazil continues to grapple with significant social inequalities, especially affecting individuals from certain ethnic groups (particularly African Descendants), impoverished communities, and people with disabilities (UNESCO, 2022). Approximately 24% of the population in Brazil is living with disabilities, representing around 16 million people. According to Brazilian law disability is recognized for those individuals persistently living with impairments that constrain full participation in society (Borgen Project, 2022). Despite recent economic growth in Bahia, one of the North-eastern states of Brazil, it remains one of the poorer regions in the country, with high disability rates (Bercovich, 2006; Treuke, 2019b). The states capital Salvador do Bahia, and its suburb Calabar, exhibits similar to regions across the globe marked residential segregation based on income and ethnicity, with Calabar being a low socio-economic neighbourhood surrounded by middle and upper-class areas (Treuke, 2019a). Within Salvador disability rates were found to be significantly higher for low-income neighbourhoods such as Calabar compared to higher-income neighbourhoods (Santos Junior & Lessa, 1989). The majority of disability research is focused in Western countries, often disregarding the variety of intersections present in developing countries that further exaggerate barriers to participation in the community for individuals with disabilities such as poverty or ethnicity (Ned et al., 2022).

The faced socio-economic and racial segregations in Calabar are further exaggerated for individuals with disabilities through major barriers including but not limited to accessibility, outlining the need to take different ecological systems into consideration (Nel & Ben-David, 2013; Treuke 2019a). Findings from Soytemel (2013) suggest that in impoverished communities informal support systems may counteract barriers such as lack of accessibility, with this research aiming to explore the impact of different ecological systems on the daily lives of individuals with disabilities in the Calabar community (Soytemel, 2013).

Calabar da Bahia

Calabar da Bahia, located in the Northeast region of Brazil, is one of the neighbourhoods of Salvador do Bahia (Treuke, 2019a). The historical informal formation of Calabar can be traced back to the 1950s, with families from low-socioeconomic backgrounds, predominantly of African descendant, began to inhabit the area. Due to the prosperity of the region, the community is under continuous pressure from various governments and the housing industry aimed at dislocating the community (Treuke, 2019a). The area exhibits marked economic dynamism, contrasting sharply with the middle and upper-class neighbouring areas, while highlighting the extensive gaps in access to resources, infrastructure, and housing (Treuke, 2019b). Surprisingly, to date no evidence was found investigating the challenges individuals with disabilities face in this particularly dynamic community. To comprehend the multi-dimensional challenges of individuals with disabilities within Calabar, a low-income community, it is essential to comprehend the different systems influencing each individual and the potential challenges within these systems.

Ecological Theory

Theories like social identity theory have been valuable in assessing the immediate systems and associated challenges for persons with disabilities, while lacking to address the complex interplay of various systems (Lundquist Wanneberg, 2014). Ecological theory however was chosen for the study, as its focus is on analysing the broader impacts of different systems, while considering social, environmental, and personal influential factors (Kaderavek, 2011). Bronfenbrenner's ecological theory of human development has thereby been widely utilized within research and educational contexts, yet, its use to understand the experiences of individuals with disabilities has been limited (Bronfenbrenner, 1979; Sontag, 1996). Individuals with disabilities residing in lower socioeconomic communities, such as Calabar, experience various disadvantages across different system within their daily life including individual characteristics, poverty, lack of resources, and cultural beliefs (Nel & Ben-David,

2013). Ecological theory integrates the unique characteristics of each individual with different interrelated systems including the microsystem, mesosystem, exosystem, macrosystem, and chronosystem (Hamwey et al., 2019; Kaderavek, 2011). These systems in combination with environmental influences shape the human developmental life course, with the four main pillars being processes, people, context, and time. It is vital to consider the influences of each system and the potential challenges arising for individuals with disabilities within the systems, noting that systems are intertwined and inherently affect one another.

Individual Characteristics

Individuals come from diverse backgrounds encompassing different ethnical, socio-economic, gender, and age experiences. One mainstream approach is not applicable to everyone without proper adjustments, particularly within the Calabar community, characterized by low socio-economic opportunities and a majority African heritage (Frisby & O'Donohue, 2018; Santana & Taffarel, 2021). Taking into account the intersectionality of disability and two existing minority groups (lower socio-economic standing and African heritage) among the majority of Calabar residents, individuals with disabilities face additional barriers. Racial discrimination was found across Brazil, limiting economic opportunities (Mitchell-Walthour, 2017). Unmet needs for assistance due to lack of resources and barriers to participation due to lack of access must be considered (Hunt et al., 2022). Research outlines that individuals with disabilities often encounter difficulties in accessing public services due to lack of accommodations in public places and transportation, with Brazil being rated very low on disability access (Garcia-Navarro, 2015).

Microsystem and Mesosystem

The microsystems encompass the individuals, or groups, a person has formed interpersonal relations with and is in re-occurrent direct contact with (Kaderavek, 2011). Family, school, and neighbourhood influences on individuals with disabilities have to be considered, particularly reflecting on their potential heightened influence on individuals daily

functioning due to lack of formal resources (Bronfenbrenner, 1994; Ferreira dos Santos et al., 2020). Across Brazil informal support systems play a vital role, as formal support structures are often either non-existent, under-developed, or under-resourced (Hunt et al., 2022). Within low-income communities, informal support networks including kin and non-kinship ties, provide essential support not only for individuals with disabilities, but for communities as a whole and minority groups, such as elderly. The reliance on these networks is even more prominent when formal services from the state or city are lacking (Cantor, 1979). Individuals with disabilities often rely on informal networks, particularly favouring family networks, to ensure access to physical and financial support, meaningful and necessary participation in the community, and securing equal rights (Hunt et al., 2022; Schneider et al., 2010; Vasquez Encalada, 2021).

Across multi-challenge low-income families there is often a combination of formal and informal strategies implemented to address needs, while it is noteworthy that some evidence suggests adverse consequences of informal support networks (Desmond & Travis 2018; Sousa & Rodrigues, 2009). Considering the multitude of access barriers faced by individuals with disabilities in Brazil and heightened importance of informal support networks, joined with intersections of ethnicity and socio-economic status the study focuses on a region in Brazil where these challenges are particularly pronounced. The multitude of intersections with disability needs consideration as previous research often limits the focus on intersections or focuses solely on gender and age, highlighting the relevance of the current investigation (Hernandez-Saca et al., 2018).

The mesosystems depict the relations between the various microsystems, and in the case of Calabar, also the community's excluded positioning among the surrounding neighbourhoods, representing a unique challenge (Kaderavek, 2011; Treuke 2019a, b). Social avoidance from the elite neighbouring areas intensifies struggles among several microsystems (Treuke, 2019a,b).

Exosystem and Macrosystem

The exosystem contains the outside frameworks whose actions affect the person whereas the person is not directly participating in them, while the macrosystem constitutes the cultural surrounding, determining the social structures, including policies, outlining the imperative to investigate these policies and protections concerning individuals with disabilities in the given context (Bronfenbrenner, 1994; Kaderavek, 2011). Calabar inhabitants not only face social avoidance but have unmet material needs due to social segmentation, affecting their access to hospitals or schools, reinforcing social hierarchies (Treuke, 2019a). Statistical discrimination has had disastrous consequences on the economic integration of the community. In response to statistical discrimination and drug trafficking within the community, the Military Police implemented activities to minimize the narcotic trade, fostering stronger connections among different microsystems of Calabar's inhabitants (Carade, 2018). For a deeper comprehension of the social relations of the community, please refer to the social map of the Family Health Unit Calabar (see <https://zenodo.org/record/7392563#.ZHcmRKXP1PY>) (DaSilva et al., 2022). A community library was also built to account for lack of resources and foster community belonging, while aiming to improve the social standing of the neighbourhood (Freitas et al., 2015).

Brazilian social policies have historically been and are still prevalingly demonstrating ableism, marginalizing people with disabilities, resulting in adverse mental and physical health outcomes (Panisson et al., 2018). Aspects such as assistive devices including mobility aids are theoretically being provided through the universal health coverage in Brazil, with many developing countries, including Brazil, struggling to provide appropriate and affordable devices to those in need (Toro-Hernandez et al., 2019). Despite the established Unified Health System, a public health care system designed to serve all individuals, there are significant inequalities in access to healthcare (Younger 216).

Furthermore, extensive research documents strong prejudice against individuals with disability within Brazilian society, resulting in limited employment opportunities and major wage gaps compared to their non-disabled counterparts (Castro et al., 2019; Guimaraes et al., 2018; Toldra & Santos, 2013). Despite the lawful implementation of disability quotas, many hurdles in the employment sphere remain and limiting social participation persists, with many individuals lacking necessary accommodations to their work environments (De Araujo et al., 2022; Maestas et al., 2019). The National Health Policy for Persons with Disabilities improved the positioning of individuals with disabilities, though previous ultra-right governments once again weakened social policies evading the state's role and responsibilities (Lyra et al., 2022).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) serves as a human right instrument, outlining the rights and freedoms of individuals with disabilities, while explicitly identifying practices and systems needed to adapt to ensure these rights (United Nations, 2006). Currently, there is a notable shift of focus to community-based support, moving away from institution-based support for individuals with disabilities, to promote participation and rights of all members of society. However, despite various international directives aimed to ensure the participation and rights of individuals with disabilities in society there are still various unmet needs especially among low and middle-income countries (Hunt et al., 2022). According to the World Bank, Brazil is classified as a middle-income country, with Calabar da Bahia being a low-income neighbourhood, exhibiting vast socioeconomic disparities, highlighting the potential presence of unaddressed needs for individuals with disabilities.

Chronosystem

The chronosystem depicts the influence of change and consistency throughout all of an individual's settings, constituting the outermost layer of all ecological systems (Hamwey et al., 2019). Over the last four years, governmental funding cuts across Brazil, coupled with the

world-wide COVID pandemic, diminished many social initiatives and economic opportunities for minority groups, including individuals with disabilities (Ferreira dos Santos et al., 2020).

The Present Study

The current study aims to provide a more comprehensive understanding of the challenges faced by individuals with disabilities in the Calabar community, encompassing the perspectives of individuals with disabilities and their support systems including primary caregivers and community leaders. Drawing upon an ecological theory framework, the study aims to reveal the different influences on the daily lives of individuals with disabilities exerted by various systems and their bi-directional relations with individuals. Prior studies highlighted the importance of considering interrelated systems, while a notable shortcoming has been the predominance of ableism-focused studies (Mello, 2016). Additionally, there is a dearth of research on individuals with disabilities across Brazil, with this research seeking to bridge that gap (De Cunha et al., 2022). The choice of Calabar as the study context is advantageous due to the different intersections within the community. The majority of research tends to concentrate on one minority group or specific disadvantaging factors in isolation, often disregarding the complex relationships and social characteristics at play (Moodley & Graham, 215).

Research Question

What is the impact of different ecological systems on persons with disabilities in the Calabar community in daily life?

Method

Study Design

The study utilizes a qualitative research design implementing semi-structured interviews accompanied by naturalistic field observations. This design was chosen as it allows for in-depth exploration of participants' experiences and perceptions about the topic on investigation (De Jonckheere & Vaughn, 2019).

Participants

The study is comprised of a total of eight participants including two men and six women, with an average age of 58 years ($SD = 16.19$, range = 33-85), all identifying as Black. They were given stone and gem names with Portuguese spelling instead of real names to ensure anonymity, while warrant individuality. Participants included two wheelchair users (Onix; Agata), one individual with a motor and visual disability (Cornalina), two primary caregivers (Berilo; Fluorita), and three community leaders (Granada; Ametista; Pirita). Only persons with bodily disabilities were selected to focus the research on a specific group, and reduce potential confounding factors associated with other types of disabilities.

Materials and Interview Guide

The opening questions for the semi-structured interviews were “Describe your daily life experiences living in the Calabar community?” for persons with disabilities, and “What are your experiences with individuals with disability in your daily life in Calabar?” for support system members. For some participants follow-up questions were used to ensure that the main topics of research were covered.

For individuals with disabilities the semi-structured questions included “What are some of the challenges you experience in your daily life?”; “How do you usually react to those challenges?”; “Who do you usually ask for help when you encounter those challenges?”; “What kind of help/support did the person/people/organisations/etc. you ask for help provide?”; “How did you arrive at the choice of support/help you needed and was the help provided as you expected?”; “If it was not as you expected how did it differ from your expectations?”; and “What were the barriers you faced to receive the support/help you feel you would have needed for your challenges?”

For support system members the semi-structured questions included “What are some of the challenges you know people with disability face in Calabar?”; “How do you assist people with disability?”; “Who in the community do you work with when assisting people

with disabilities?"; "What kind of help/support did the person/people/organisations/etc. you work with provide?"; and "What are the barriers you know about to receive support/help for people with disability?".

All participants were asked descriptive questions including gender, age, current work situation, and ethnicity.

Procedure

To recruit participants the staff employed at the University of Bahia was utilized, specifically from the culture research group, as they had already on-going projects in the Calabar community. Participants were either previously known to the research group, approached on the streets of Calabar, or referred to from other members in the community. Interviews were conducted face-to-face after receiving informed consent in the homes or workplaces of participants within the Calabar community during March 2023 to warrant an in-depth understanding of the local setting and to aid participants' comfort (Neville & Reicher, 2011). The length of interviews ranged between 9 to 48 minutes ($M = 30.33$, $SD = 15.10$), with Dictaphone used as a recording app. All interviews were conducted in Portuguese and later translated to English.

Ethics

Written informed consent was obtained from all participants. To ensure participants' confidentiality and anonymity all identifying information was removed from transcripts and participants were referred to by their given stone and gem names. The data collected in Calabar da Bahia, Salvador da Bahia, Brazil was securely stored on the TSD server of the University of Oslo. NSD (reference number: 965734) approval was received for the study. The researcher abided by the Norwegian Code of Ethics, taking into account cultural considerations for field work, specifically for non-Western countries (Honan et al., 2013). As a researcher entering a local Brazilian community from abroad without prior knowledge of the local language, the authors reflexive positioning is characterized by a recognition of personal

linguistic limitations and reliance on the local research-tandem partner for translations (Smith et al., 2008). The author critically reflected on power dynamics and potential biases due to this limitation, while acknowledging the valuable insights gained through collaboration with the local partner. The researchers tried to establish a balanced and respectful dynamic between themselves and the participants, fostering open communication and active listening to contribute to useful experience for participants and increase reliability and validity of findings (Anderson & Henry, 2020).

Data Analysis

Interviews were audio-recorded transcribed using the Autotekst software from the University of Oslo into Portuguese and English. The research-tandem partner, a native Portuguese speaker, confirmed accuracy of the transcripts after minor adjustments. Afterwards thematic analysis was used to explore the main topics of the research that emerged using the data analysis software NVivo (<https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>), which aids the organization of the analysis by accommodating qualitative data. Thematic analysis was chosen as it facilitates the identification of themes and patterns within the interview data, whereby the researcher familiarized themselves with the data, generated initial codes, searched for themes and revised them, and defined the main themes (Guest et al., 2011).

Results

There are four major themes that emerged during the interviews with participants: (1) Access challenges faced by individuals with disability, (2) Poverty intersection with disability, (3) Discrimination intersection with disability, (4) Importance of support systems for individuals with disability.

Theme 1: Access Challenges faced by Individuals with Disability***Physical, Transportation, Financial, and Healthcare Access***

Participants highlighted significant challenges in regards to physical- and transportation access. Physical access was a major concern throughout all interviews due to uneven pavements, significant slopes, and steps across the entire community, with Granada stating, “Calabar is a place with a lot of stairs, the access is bad, and the assistance for people with disability is complicated.”, and Berilo mentioning, “Because the wheelchair it broke, due to many obstacles because of the road”. Partial implementation of ramps for wheelchair users was reported by Ametista, “We also managed to make a ramp of accessibility for the home.” Public transport access was reportedly difficult to use due to high entry steps, and use of alternative transport methods often a financial barrier for participants. Fluorita stated, “The buses...Right now we took one. The height was huge for her to climb. I had to lift her. (...) I don't even know if I have the money to pay the car instead.” Lack of in-house physical therapy and restricted access to physical therapy options were also reported. Fluorita mentioned, “The doctor we tried for her to receive the support of physiotherapy for that disability. He refused to give her a prescription.” Both Berilo and Fluorita also mentioned limited access to job opportunities, and no governmental support for primary caregivers.

Autonomy and Information Access

Numerous participants reported hindrances to living an autonomous life due to dependency of individuals with disabilities on support systems.

Agata: “The biggest barrier was how I was going to do it, to move myself, to go to the emergency, to go to the doctor, because it is a battle, a battle of years. I need three people to carry me. I cannot do it alone. I need a lot of people.”

Participants conveyed a lack of access to information about disability and available assistance in the community, while however support programs were mentioned for individuals

suffering from domestic abuse, and children. Also, some local resources such as a community library with braille books were reported.

Theme 2: Poverty Intersection with Disability

Basic Needs, Education, and Work

Participants outlined the intersection of poverty and disability, pointing out the lack of access to basic needs and resources due to low socio-economic standing. Agata reported experiencing hunger during certain periods, stating, “During this period of this Bolsonaro government, I was hungry.” Berilo mentioned the lack of necessary equipment and resources, mentioning that even though a wheelchair was funded by governmental resources, it broke after a short amount of time, and the family lacked the monetary necessities to repair it. Due to poverty, education and work opportunities were also reportedly inadequate, due to lack of adjustments to the environments to accommodate special requirements with Berilo stating, “Until he was 15 years old school he attended and then it stopped. The problem came from the broken wheelchair.”

Poor Health, Violence, and Segregation

Cornalina stated poor health conditions were faced in the workplace due to poverty, initiating and exacerbating the disability, “I washed a lot of clothes, made clothes, and we used burned coal to set fire to be able to light an iron. The temperature of that made my eyes sick.” Several participants mentioned the prevalence of violence in the community due to poverty, increasing the vulnerability of individuals with disabilities, with Granada stating, “We have violence, which is a factor that restricts those who do not have accessibility” and Fluorita outlining how the individual she is a caregiver for does not like to be outside explaining, “In the event of a shot or a robbery. So, she gets very scared.” Participants also reported segregation of Calabar to the neighbouring communities due to socio-economic

standing further impacting health support, as neighbouring communities had better access to facilities.

Theme 3: Discrimination with Disability

Participants stated facing discriminatory treatment based on disability. Stereotyping perceptively influenced how individuals were treated increasing fear and sense of vulnerability, with Cornalina stating, “I fell from the bus. (...) I never found help.” Also, negative impacts of systemic discrimination of vulnerable communities were outlined, with Granada stating, “What we had was a violence generated by the state, that the state always ends up violating these vulnerable communities.”

Theme 4: Importance of Support Systems for Individuals with Disability

Participants emphasised the importance of practical assistance through support systems to ensure the well-being of individuals with disability. Aspects such as mobility assistance were crucial due to the inefficient physical accessibility in the neighbourhood and surrounding areas. Individuals with disability reported to be reliant on support systems to assist them outside their homes and maintain their independence, with Berilo stating, “He did not have a wheelchair. I took him on my back from here to there to do physiotherapy.”

Discussion and Implications

The current study aimed to provide valuable insights into the challenges of persons with disabilities in the Calabar community, through the lens of ecological theory. The preceding thematic analysis demonstrates the different contextual factors, which will be discussed against the various ecological systems and how the systems intertwine to pose certain barriers to the daily life in the given context. Within this study four major themes emerged including 1) Access challenges faced by individuals with disability, 2) Poverty intersection with disability, 3) Discrimination with disability, and 4) Importance of support systems for individuals with disability. Analysing the results through the ecological approach

aids the comprehension of the dynamic and bi-directional relationships between individuals with disability and their different influential environments.

Access challenges faced by Individuals with Disability

The first major theme of access challenges faced by individuals with disability aligns with the macro component of ecological theory. The lacking physical and transportation access demonstrates the imposed barriers by the surrounding environment, influenced by aspects such as lack of funding or inefficient social policies, which have to be considered, as evidence suggests that it is important to feel like a productive member of the community (Alfrey & Jeanes, 2023). Insufficient accessibility to appropriate infrastructure in the community and city as a whole, such as uneven pavements and a multitude of steps, largely impairs the mobility of individuals with disability, restricting participation in the community. These barriers influence individuals' participation not only on a social level but also impact educational and employment opportunities, whereby even though quotas for employment of individuals with disability are implemented across Brazil, none of the participants with disability were employed, outlining the influence of access barriers, lack of qualification, and discrimination (Neves-Silva et al., 2015). These challenges highlight how the shortcomings in the macrosystem constitute constraints to the individual and the microsystems. To address these challenges using the ecological framework, the physical environment in the community and city should be modified to increase accessibility to individuals with disability and other disadvantaged groups such as elderly through implementation of ramps, improved road conditions, and more inclusive public transport.

In line with previous research findings there was also a gap of access to community support services such as the local health care centre (Hunt et al., 2022). Several community members mentioned the availability of the health care services within the community, which was difficult to access however, due to lack of transport options. This demonstrates how ensuring physical accessibility in laws on a macro-level influences the access to healthcare for

the individual. Interviews reported that no home services including doctors or physical therapists were available for individuals with disability. Even though in legislation the equality of availability of health care services to all individuals is clearly outlined, there are vast physical barriers and dependencies on socio-economic status in reality that hinder individuals from proper health access. This needs to be addressed on a governmental level, demonstrating the macro influence, as these aspects were shown to not be able to be covered by family or community support, on a micro level (Younger, 2016).

Considering lack of information and resource access reported by several participants, there were some resources available for certain disabilities, such as braille books through the community library, with those community facilities needing more local and state funding to expand their resources. Nevertheless, it was reported that several blind individuals did not have the resources to learn braille, which would make the availability of braille books redundant to them. Braille workshops would therefore have to be implemented first, which could be done as an aspect of already different implemented workshops for female support or historic roots teaching that aids the community's sense of belonging as a whole (Freitas et al., 2020).

Poverty Intersection with Disability

The intersection between poverty and disability in the community aligns with the economic and social aspects of the ecological framework, touching into all environments. Poverty affects the availability of resources and opportunities across varying domains for individuals with disability, with lack of access to basic needs, education, or employment opportunities on an individual level, outlined by participants demonstrating the socio-economically disadvantaged positioning of the community. Research often disregards the intersection between poverty and disability, which is problematic. Individuals might have the same disability, yet their available resources and opportunities can vary largely depending on their socio-economic positioning (Hosseinpoor et al., 2013).

Within the ecological framework the socio-economic context of individuals has to be understood to comprehend the lived realities and develop realistic and applicable interventions (Golden & Earp, 2012). Multi-level approaches should be implemented including but not limited to economic empowerment and policy changes on a macro-level, such as adjustments to the Continuous Cash Benefit Programme to support individuals with disability, as none of the current participants were currently included in the program (Medeiros et al., 2015). Shortcomings on the macro-level therefore once again constructed barriers for individuals and their microsystems. Primary caregivers thereby struggle with their caregiving obligations and employment, demonstrated through interviews outlining that they did not manage to fulfill their caregiving obligations while working full-time. However, they neither receive a compensation for their caregiving role nor are considered for financial support schemes, which should be re-evaluated on the appropriate macro-level influences. Efforts should be placed on reducing the aforementioned social inequalities, and decrease barriers to inclusive economic development, to support individuals with disability and their caregivers in improving their socio-economic positioning, as poverty and disability can double disadvantage individuals (Moodley & Graham, 2015).

Discrimination with Disability

The intersection of discrimination and disability demonstrated the cultural and social aspects of the ecological framework, reflecting the macro level influences, as experiences of stereotyping and prejudice faced by some participants reflect cultural beliefs, social norms, and attitudes across the community and potentially the city and country as a whole (Kaderavek, 2011). Discriminatory behaviours and actions increase barriers to participation and perpetuate social exclusion, outlining how the outer layers of ecological theory influence the individual on a daily base (United Nations, 2018). Based on ecological theory cultural and social aspects need to be adapted to increase inclusivity of all minority groups and provide equal rights to all citizens. On a policy and social level, reflecting the macro and also chrono-

level aspects, the historically-rooted memories of suppression of Black people in Brazil, and the history of slavery have to be taken into consideration in the given context (Treuke, 2019a). It is essential that governments and researchers increase awareness of the disadvantaged positioning individuals with a double minority of African heritage and disability face, compared to Caucasian individuals with disability (Younger, 2016).

There was a lack of mention of any implemented programs to support inclusion of people with disability across microsystems, with previous evidence suggesting that effective interventions for changes in the perception and awareness of disability can reduce intergroup bias and increase social inclusion (Babik & Gardner, 2021). These findings demonstrate how adjustments in the microsystems can influence the adjustments of cultural values on the macro-level. Educational efforts, awareness campaigns, and anti-discriminatory policies have to be put in place on a macro-level, especially considering the multi-layered intersections present in the Calabar community for individuals with disability having a majority of members from African descent and low-income socio-economic standing, while not even having considered further intersections such as age and gender (Boring & Philippe, 2021).

Importance of Support Systems for Individuals with Disability

The importance of support systems for individuals with disability aligns with the microsystem and mesosystem components of the ecological framework (Kaderavek, 2011). Participants reported the major role of their microsystems including family and friends in providing practical assistance especially for physical access limitations, and aiding independence in daily life, while however support systems could not counteract the complexities of different lacks of access completely. Several participants mentioned issues within the mesosystem, as a lack of communication among microsystems was reported. Several social inclusion and support programs were found for victims of domestic violence or children implemented by the military police station in the community. Yet, no specific program for individuals with disabilities is currently available due to the differing struggles of

so many groups within the community that took precedence as they were either larger or more publicly visible. Support networks should therefore be strengthened and expanded to account for the needs of individuals with disability on the micro- and meso-level, while taking into consideration the previously mentioned access, poverty, and discrimination aspects, to decrease barriers of individuals with disability in Calabar (Holanda et al., 2015). Improving support networks might also improve experiences of caregivers, which in low-economic communities might face challenges due to their role (Ae-Ngibise et al., 2015)

Strengths and Limitations

Using a diverse sample of persons with different disabilities and various support systems provides a broad overview of the challenges offering insights from multiple perspectives, with the representation of diversity being particularly important in qualitative research due to the small sample size (Allmark, 2004). Yet, the small sample size limits generalizability, while however, different ages, backgrounds, and positions in the community were covered to mitigate this limitation (Tipton et al., 2017). Acknowledging the intersections of poverty and ethnicity, offered a more nuanced comprehension of the challenges of persons with disability, often overlooked in research (Moodley & Graham, 2015). Having a diverse sample might also increase variations of experiences and associated challenges. Future research should therefore focus on specific disabilities and their associated challenges within the community. Furthermore, the main focus was the challenges faced by persons with disabilities, with no extensive exploration of the experiences and needs of caregivers. Future investigations should explore the specific challenges and needs of caregivers in particular, as they reportedly were a major influence on reducing barriers for persons with disabilities.

Conclusion

The current study applied an ecological perspective to provide a comprehensive understanding of the challenges of persons with disabilities in the Calabar community in Salvador da Bahia, Brazil. Findings portrayed that there is a major lack of different forms of

access, particularly physical access, which was partially counteracted by community support, while however major barriers remained. Results demonstrate that shortcomings on the macro-level impact the individual and associated microsystems, who often aim to account for broader imposed barriers. Intersections between disability, poverty, and discrimination further disadvantaged individuals, while support systems played a critical role in ensuring quality of life for individuals with disabilities. Using the ecological perspective points out the need for multi-layered interventions, addressing environmental barriers, socio-economic disparities, cultural beliefs, and enhancing support systems. Acknowledging the interconnectedness of individuals and their environment is crucial in developing holistic approaches to improve the lives of individuals with disabilities and the community as a whole in the given context. Future research should investigate the effects of different intersections in the community further, placing focus on the specific needs of particular disabilities. Additionally, it is imperative to investigate the needs of caregivers of individuals with disabilities in the community, due to the absence of previous studies on the topic. Comprehension of the unique challenges of the microsystems of individuals with disabilities will contribute in improving informal support networks that in the current study minimized challenges imposed through macro-level shortcomings.

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